

## **Screening for psychological distress in cancer: renewing the research agenda**

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## **Abstract**

*Objective:* Although health policy for cancer care promotes screening of patients for emotional distress, the utility and validity of screening **have been questioned**. Continued research to refine detection of distress or to evaluate outcomes of screening programmes is unlikely to end this controversy. Instead, we need to identify more fundamental research questions that address the validity or utility of screening in this context.

*Method:* We critically and selectively review research and policy literature on psychological screening in cancer care, drawing also from research literature about the nature of psychological needs in cancer care and from relevant literature on psychological screening in mental health.

*Results:* We identify three broad research questions: (i) Apart from intensity of distress, what further information should screening seek about the context of distress, psychological processes that promote distress, and patients' own perspective on their needs? (ii) What are the implications of the contextual dependence of disclosure of emotional feelings, given that screening questions can be asked in contexts ranging from an impersonal questionnaire to dialogue with a trusted practitioner? (iii) How should a screen be responded to, given the inherent uncertainty associated with screening results and given that distress in a cancer context can indicate instrumental as well as psychological needs?

*Conclusions:* Examining these questions will mean exchanging a diagnostic framework for screening, in which health need is indicated by presence of a psychological disorder, for a public health framework, in which health need is identified from multiple perspectives.

**Keywords:** Cancer; Oncology; Distress; Screening; Psychosocial; Patient perspective

## Introduction

As cancer therapy becomes more effective, the population of people being treated or followed up for cancer or who have survived the disease grows. There are now over 13 million cancer survivors in the USA[1] and around 2 million in the UK[2]. However, cancer remains a life threatening diagnosis with profound psychological impact even years after treatment has ended. Therefore health policy in many countries over the last decade has prioritised detecting and addressing psychological needs associated with cancer. Routine ‘screening’ of cancer populations for emotional distress is at the centre of these policies. In the UK, USA and Canada, policies recommend that health care practitioners should screen for distress at key points in the patient pathway from diagnosis to end of treatment and through any recurrence. The aim is to reduce distress in this population by ensuring that patients receive the psychological help that they need from clinical staff or specialist psycho-oncology services[3-5]. The validity and utility of screening have been challenged, however, some critics arguing that the resources invested in screening programmes would be better deployed in other ways to improve the mental health of the cancer population[6-9].

Evaluations of whether psychological screening programmes benefit patients do not resolve this disagreement. Although there is some evidence that screening improves clinicians’ and patients’ communication about psychological needs[10, 11], evidence that screening programmes improve detection of patient distress and thereby improve patient wellbeing has been inconsistent[8, 12-15]. Moreover, continued research of this kind is unlikely to resolve disagreement over the value of screening. Outcomes of screening depend on the specific configuration of psychological services and support available[14], so generalisability of these kinds of findings is inevitably limited. Research on improved screening methods continues apace, with a burgeoning literature reporting new or modified screening instruments and their psychometric properties. However, more fundamental challenges for screening research are less commonly addressed.

## **Aims and methods**

Our aim was to indicate priorities for future screening research by identifying challenges to the validity and utility of psychological screening in cancer care in general, rather than of specific screening instruments. However, screening literature focuses heavily on psychometric properties of specific instruments. Therefore, rather than review this literature comprehensively, we selectively reviewed papers and guidelines over the last decade that helped identify the key features and underlying assumptions of screening research and policy literature. We also draw on research evidence about the nature of psychological needs in cancer care, and on research into detection of psychological needs in mental health settings, where this could inform dilemmas for psychological screening in cancer care. We identify three broad questions that research will need to address if the potential of psychological screening in this population is to be understood.

## **Results**

*What information should be sought?*

### *Context and trajectory of distress*

Currently, screening overwhelmingly emphasizes the level of distress, with less attention to the context of the distress. However, distress is a normal reaction to cancer, usually transient and subsiding over time[16, 17]. Patients' readiness to see distress as a problem that should be addressed also changes over time[18]. Therefore a positive screen for distress is likely to mean different things at different times. Soon after diagnosis or learning of recurrence, or after an unrelated life event, it might be a normal acute stress reaction, needing understanding and support from practitioners caring for the patient. When it persists a year or more after successful treatment, it might signify relapse of a premorbid psychological disorder needing specialist intervention[19]. There are potential lessons from managing patients with acute stress reactions in mental health settings, where it is well

known that even patients with post-traumatic stress disorder (PTSD) can recover naturally within a month of presentation[20]. Moreover, it is now appreciated that psychological intervention in the immediate aftermath of a trauma can be damaging. In particular, the once popular approach of ‘psychological debriefing’ is now thought to worsen PTSD symptoms, especially in the most vulnerable patients[21]. Clinical guidelines for PTSD therefore recognise that a single assessment can be misleading about need for psychological treatment and recommend, instead, watchful waiting with follow-up within one month[22].

This is not to argue that distress at the time of a crisis never needs a psychological response while that a year or more later always does; rather, a screening instrument that asks the same questions, and interprets the answers in the same way, throughout the cancer trajectory is unlikely, alone, to be informative. Therefore the current ‘one-dimensional’ concern with intensity of distress needs to be broadened to include more information about the context of the distress. While ‘problem checklists’ provide some additional information to contextualise distress ratings, research reports often disregard them in reporting the need for psychological referral[23-25]. Moreover, problem checklists do not prompt practitioners to examine aspects of context beyond the problems listed, particularly the timing of distress in relation to adjustment processes. Despite evidence that brief screening instruments can detect change over time[26, 27], research still has to address, for example, whether screening at certain points in the cancer journey is more informative than at others, or whether persistence of distress over more than one assessment point better indicates need than do point measures[8].

### *Processes and risk factors*

Extending screening beyond distress also has the potential to yield information that could help practitioners to identify in advance those at risk of persistent or severe distress. Dekker et al[28] and Enns et al[27] suggest that screening should assess demographic, social or clinical characteristics that confer resilience to the trauma of cancer. Additional premorbid characteristics, including history of emotional disorder or childhood abuse, can help identify

patients at risk of severe or persistent distress[29]. However, while risk factors like these can help *predict* distress, they do not themselves provide targets for intervention to *prevent* distress. A target for screening research could be to identify the psychological processes that lead to persistent or intense distress, can be detected by screening and, ultimately, can be targeted by preventative psychological treatment. This approach has been rare, but its potential is illustrated by a report that dissociative symptoms shortly after cancer diagnosis helped identify those patients who went on to have post-traumatic stress disorder 6 months later[30].

### *Patients' perspective*

Enthusiasm for psychological screening in cancer probably owes much to the widespread acceptance of the validity of biomedical screening, such as mammography for breast cancer or faecal blood sampling for lower gastrointestinal cancer. However, whereas biomedical screening normally reveals something occult in the body that the patient cannot otherwise know, screening for psychological distress is fundamentally different. Using screening questionnaires, practitioners cannot discover a patient's thoughts or feelings beyond what the patient already knows and chooses to disclose.

Therefore, it seems potentially disempowering of patients for experts to rely on patients' answers to their questions to *tell* patients whether or not they *need* help. The alternative is to *ask* patients whether they *want* help[31]. The answer will often be different. Many patients who screen positive for emotional distress do not want psychological help[32, 33]. In studies across five countries, only around half or fewer of patients who screened positive for distress had sought – or intended to seek – professional psychosocial help[34] or indicated that they were interested in it[33, 35, 36]. Where patients with positive screens were offered referral to psycho-oncology services, only a quarter accepted[37]. Distressed patients who did not want professional help relied on family and friends or preferred not to talk about their problems[36]. Conversely, many patients who do not reach screening criteria for distress do want psychological help, reported proportions ranging from 9% to 33%[33, 36,

38]. Many patients seek help for interpersonal or existential needs that might not be detected by measuring distress[31]. In screening literature, however, patients' preferences have often been regarded as mistaken where they diverge from results of distress screening. For example, patients' negative responses to a question asking whether they want help have been described as potentially 'reducing sensitivity' of screening[35, 39]. That is, the habit of privileging the 'expert' perspective devalues patients' perspective.

Recognising patients' potential role in deciding on psychological need points to the importance of research that explores how this role can be supported or enhanced. That is, to complement research into how practitioners can improve screening instruments to make better decisions, we need research that explores how patients can be empowered to decide when they need psychological help and what they need. Simply providing information and signposting about services might prove more valuable than screening[7]. However, distress screening does yield certain kinds of information that patients cannot otherwise know and that it might prove helpful to feed back to them, a positive screen indicating, for example, that distress is high compared to most people, or that the patient is distressed to a level which would normally entitle them to professional help. Whereas research has examined effects of giving patients summaries of their concerns[40, 41], it could go on to examine whether adding relative or conditional information of this kind might enhance distressed patients' readiness to take up psychological help. In contrast with the 'triage' model, relying on experts' judgments or algorithms for what patients need[6], this approach would emphasise empowering patients to make their own choices.

*(How) should screening be integrated into the clinical relationship?*

The language of 'screening' in mental health evokes the greater objectivity of screening in physical health, where screening procedures are typically assumed to be contextually robust – for example, a mammogram should ideally deliver the same results wherever it is administered or whether it is administered by a kindly or brusque practitioner. In cancer, however, what is revealed is likely to be highly contextually dependent[42]. For

example, as a single-item screen, a patient would probably experience the question ‘Are you depressed?’[43] very differently depending on whether it is asked by a practitioner looking at a computer screen or one who asks empathically in response to the patient seeming tearful. Nevertheless, policies vary in the context they envisage for psychological screening questions, from computer administration[5] to consultation with a trusted practitioner[44]. Australian guidance was cautious about self-report questionnaires, preferring targeted questions within clinical consultation[45]. Even within the UK, practice diverges, patients variously being asked to complete screening on a questionnaire mailed to their homes[46], in a waiting room[47, 48], by telephone[49] or within consultations[44].

In the context of cancer care, it is not clear whether disclosure is better facilitated by the anonymity of automated assessment or, conversely, the safety of a clinical relationship. Different patients might disclose more readily with different approaches[50], and different approaches might be needed at different stages of the illness trajectory[51]. That is, multiple methods might be better than a single method. Unfortunately, there is little evidence to guide services. Therefore a priority for research is to compare screening presented in different contexts and to identify the methods, or combinations of methods, that best enable patients to disclose emotional needs[8].

*What responses should follow a screen?*

#### *Managing uncertainty in screening*

Classic biomedical screening normally identifies, not patients who need treatment, but those with elevated risk of disease who need further assessment to confirm whether they need treatment. For example, a positive screen for faecal blood might be followed by colonoscopy and biopsy for definitive diagnosis. Results of psychological screening are similarly probabilistic. Screening instruments are normally validated by reference to a clinical interview, so they indicate the probability that patients would be assessed as distressed if they underwent that interview. In practice, therefore, psychological screening has appreciable



error. Using conventional thresholds to detect distress with ultra-short screening instruments, almost all patients screening negative would not be distressed according to a clinical interview but only around a third with positive screens would be[52]. Even stated specificities and sensitivities overstate precision because, as a ‘gold standard’, clinical interviews are themselves unreliable, especially in the context of cancer[53]. Moreover, screening instruments are often validated poorly or by comparing them with another questionnaire or screening instrument, further inflating uncertainty surrounding the results of screening[46, 54, 55].

Different screening guidelines offer different advice for what should follow a positive screen, while generally assuming that a negative screen needs no exploration. UK guidance envisages that positive screens should normally lead directly to offers of psychological support[3]. However, policies – and research reports – that interpret positive screens as, alone, indicating emotional distress mistake screening for case-finding[28, 56]. Therefore USA and Canadian guidance advocates clinical assessment before considering referral for psychological intervention[4, 5] although without providing explicit guidance for what such an assessment should entail or how the decision about what help is needed should be made.

What should follow a positive screen is therefore potentially as important a research topic as the properties of the screening instrument. For example, studies could compare case-finding by clinical assessments from specialist and clinical staff or by further self-report questionnaires. In addition, because a proportion of patients with negative screens are wrongly identified as not needing psychological help, research also needs to examine what should follow a negative screen. In one sample, interviews following screening questionnaires identified psychological needs in a quarter of patients who had not self-identified as distressed on the questionnaires, or who had declined to complete them[38].

### *Judging the need for explicitly psychological intervention*

Perhaps because of the widespread assumption that screening ‘detects’ psychological disorders, and despite warnings that positive screens warrant further assessment[6], research literature often equates positive screens with need for explicitly psychological intervention, for example in using the language of psychological disorders[42, 52, 57] or of ‘diagnostic accuracy’[58], or in advocating referral to a psychological practitioner for patients reaching a threshold score for distress[23-25, 59]. The concept of psychological disorders is, though, contested, critics arguing that distress should be understood in its context[60]. In cancer, the crucial context is that patients are in mortal danger – in striking contrast to mental health settings where psychological intervention would not normally begin until patients are physically safe. When people feel in danger, emotional distress has wider functions than to communicate need for psychological help. Faced with a life-threatening diagnosis, emotional distress can indicate need for an instrumental response from a clinician, such as symptom relief or treatment planning[61-63]. In a sample of cancer patients attending community care, there were more distressed patients who wanted to speak with a dietician than with a psychologist[25]. Moreover, when patients attend for physical health problems there is no implicit contract to seek or accept psychological help. Distressed patients or families can sometimes prefer not to address emotional distress in cancer consultations, to the extent of preferring that doctors do not enquire about psychosocial matters[18, 64]. Indeed, clinicians’ avoidance of psychological talk can be crucial to the emotional comfort and reassurance that they provide[63].

This is not to argue that patients with cancer should routinely be abandoned to their distress. Rather, in the context of cancer, a positive screen for distress should not be interpreted as an obligation or expectation for patients to accept formal psychological help. Despite recognition of the importance of ‘triaging’ patients who screen positive for distress[6] research has, in equating psychological distress with need for explicitly psychological help, regarded the response to positive screens as unproblematic. Instead, research should explore in what circumstances an explicitly psychological response is needed

and how patients and practitioners can be helped to choose between different responses that might be appropriate.

### **Conclusion: from a diagnostic to a public health framework for screening research**

A major constraint on research and policy about psychological screening in cancer has been its allegiance to a diagnostic model of identifying need, according to which detecting psychological distress indicates need for explicitly psychological support or intervention. Within this model, it is natural for research to focus overwhelmingly on improving precision of detection. We have argued here, however, that this is to pursue a chimera that obscures more fundamental questions about what should be assessed, how the information should be obtained, and what should happen afterwards. Research that addresses these questions will probably complicate our understanding of screening rather than simplify it; it is likely to show that deciding whether a patient has psychological needs, and how these should be met, is too complex to be reduced to a simple screen for distress.

By contrast with the simplicity of the diagnostic model, public health has long recognized that healthcare need is a complex and multidimensional concept. It offers an alternative framework for identifying needs, within which researchers can broaden their focus. As a starting-point, it recognises that there are several different perspectives from which to identify health needs[65]. The use of formal questionnaires to measure distress and bench-mark it against clinical threshold scores corresponds to only one of these perspectives: ‘normative need’, which is defined as need identified by experts. Patients' own feelings of unhappiness correspond to the second perspective, ‘felt need’; and we saw above that these might not always be exposed by screening questionnaires which reflect experts’ language of distress, anxiety or depression. Patients’ expressed wish for help corresponds to the third perspective, ‘expressed’ need. Again, we have seen that patients’ enthusiasm to seek or accept psychological help is also not clearly related to experts’ judgments of what they need based on screening questionnaires.

A fourth public health perspective is ‘comparative need’; that is, specifying and addressing a health need in one population establishes a bench-mark for what is recognised as a need in similar populations[65]. While this perspective points to the ethic of equity as a driver for service development, it also warns us of the risk that emotional distress might become, in effect, the ‘6<sup>th</sup> vital sign’ in cancer care[5], not because of the merits of the case but, to some extent, because services simply try to keep up with practices that they see implemented or advocated elsewhere.

The public health framework is therefore more realistic than a diagnostic one in recognising that there can be different perspectives on whether psychological need exists in any instance. When these perspectives align, such as when patients want help (felt need), score above a clinical threshold on a screening questionnaire (normative need) and seek or accept referral to psychological services (expressed need), their need is unambiguous. However, need is less clear where, for example, screening questionnaires identify patients who do not want help, or fail to identify ones who do. The public health approach is realistic, also, in acknowledging that different perspectives do not necessarily align. It therefore provides a framework within which researchers can pursue the questions that we have identified in order to explore to what extent alignment is possible in practice and how to respond when it is not. For example, in studying the information that screening might seek, other than levels of distress, researchers can seek to improve detection of normative need by assessing psychological processes that might predict persistent distress; or they can explore how to enhance patients’ ability to choose for themselves - ‘expressed need’. Setting aside a diagnostic model will require researchers to address how the manner and context in which people are asked about emotional matters shapes what they disclose, and how, in the context of cancer in which doctors’ and nurses’ instrumental care has powerful emotional functions, practitioners can identify when distressed patients need explicitly psychological intervention.

Turning from a diagnostic to a public health framework will bring ethical challenges, because resolving the tensions that arise when different perspectives on need do not align will

reflect the value that we attach to those perspectives. We have argued for greater recognition of patients' own perspective on their needs, which is devalued when researchers pursue psychometric refinement in the context of a diagnostic model. To inform the value judgments that arise in this field, future researchers will therefore need to be informed by ethical as well as theoretical and empirical considerations. In this way, research will expose for debate judgments that are currently hidden from scrutiny by the common assumption that realizing the potential of screening for psychological need in cancer depends simply on increasing the precision of instruments to detect distress.

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### **Conflict of interest**

The authors are aware of no conflict of interest in relation to this manuscript

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